Complete Summary

GUIDELINE TITLE

Providing spiritual care to the terminally ill older adult.

BIBLIOGRAPHIC SOURCE(S)

Meraviglia M, Sutter R, Gaskamp CD. Providing spiritual care to the terminally ill older adult. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core; 2006 Dec. 45 p. [106 references]

GUIDELINE STATUS

This is the current release of the guideline.

** REGULATORY ALERT **

FDA WARNING/REGULATORY ALERT

Note from the National Guideline Clearinghouse: This guideline references a drug(s) for which important revised regulatory and/or warning information has been released.

- May 2, 2007, Antidepressant drugs: Update to the existing black box warning on the prescribing information on all antidepressant medications to include warnings about the increased risks of suicidal thinking and behavior in young adults ages 18 to 24 years old during the first one to two months of treatment.

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

Spiritual distress

Note: In this guideline, spiritual distress is defined as the impaired ability to experience and integrate meaning and purpose in life through connectedness with self, others, art, music, literature, nature, or a power greater than oneself.

GUIDELINE CATEGORY

Evaluation
Management

CLINICAL SPECIALTY

Geriatrics
Nursing
Psychiatry
Psychology

INTENDED USERS

Advanced Practice Nurses
Health Care Providers
Nurses
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers

GUIDELINE OBJECTIVE(S)

To give health care providers evidence-based guidelines for providing spiritual care for terminally ill older adults who are at risk for spiritual distress

TARGET POPULATION

Older adults diagnosed with terminal or life-threatening illness (e.g. renal failure, heart failure, or advanced cancer) at risk for experiencing spiritual distress

INTERVENTIONS AND PRACTICES CONSIDERED

Assessment

1. Assess patient's spiritual well-being, loneliness/social isolation, hopelessness, anxiety, and depression using specific assessment tools:
    - Functional Assessment of Chronic Illness Therapy-Spiritual
    - Loneliness Scale-Abbreviated
    - Herth Hope Index

- Short Screen for Depression Symptoms algorithm

Nursing Interventions

1. Encourage relationships
2. Encourage new connections
3. Encourage hope
4. Use music
5. Use touch and massage, with or without aromatherapy
6. Encourage forgiveness/reconciliation
7. Refer to palliative/hospice care
8. Refer for psychotherapy

MAJOR OUTCOMES CONSIDERED

- Spiritual well-being
- Hopefulness
- Connectedness
- Depression
- Quality of life

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Not stated

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

The grading schema used to make recommendations in this evidence-based practice protocol is:

A. Evidence from well-designed meta-analysis
B. Evidence from well-designed controlled trials, both randomized and nonrandomized, with results that consistently support a specific action (e.g., assessment, intervention, or treatment)

C. Evidence from observational studies (e.g., correlational descriptive studies) or controlled trials with inconsistent results
D. Evidence from expert opinion or multiple case reports

METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

The guideline is developed from the authors' whole person perspective that views people as having integrated physical, emotional, social and spiritual dimensions, with spirituality at the core of human being; and the belief that alterations of well-being in one dimension affect the other dimensions.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

This guideline was reviewed by experts knowledgeable of research on spirituality, well-being and quality of life, and development of guidelines. The reviewers suggested additional evidence for selected actions, inclusion of some additional practice recommendations, and changes in the guideline presentation to enhance its clinical utility.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

The grades of evidence (A-D) are defined at the end of the "Major Recommendations".

Assessment Criteria

The following assessment criteria indicate at-risk older adults with a terminal illness who are likely to benefit the most from use of this evidence-based guideline (McClain-Jacobson et al., 2004; Murray, Kendall, & Boyd, 2004; Villagomeza, 2005. *Evidence Grade = C*).

- Inability to engage in spiritual or religious practices
- Expressing frustration, fear, hurt, or doubt
- Expressing feelings of loneliness and isolation
- Expressing lack of hope or feeling life is not worthwhile
- Expressing feelings of losing control
- Verbalizing questions about faith or loss of faith
- Expressing emotional suffering such as lack of meaning, guilt, anger.
- Evidence of anxiety and/or depression
- Expressing a desire for death
- Suicide ideation

Assessment Tools, Instruments and Forms

Several tools are available to assess patients with spiritual distress related to having a terminal illness. To effectively assess patients at risk the nurse must examine the patient for feelings of spiritual distress, loneliness, hopelessness, anxiety, and depression. Refer to the original guideline document for detailed discussion of spiritual well-being, loneliness and social isolation, hopelessness, anxiety, and depression.

- One tool useful for clinical assessment of the level of spiritual well-being is the **Functional Assessment of Chronic Illness Therapy-Spiritual** (FACIT-Sp) (version 4) (See Appendix A1 of the original guideline document) (Cella, 1997. *Evidence Grade = B*)
- A short tool for assessing loneliness is the New York University **Loneliness Scale**—"abbreviated" (Hughes et al., 2004. *Evidence Grade = C*). The Loneliness Scale-abbreviated is recommended for evaluating loneliness in older adults with a terminal illness and is provided in Appendix A2 of the original guideline document.
- The tool most appropriate for assessing the terminal ill older adult in clinical practice is the **Herth Hope Index**. The Herth Hope Index specifically assesses hope in the ill population and determines change over time in the clinical setting. (Herth, 1992. *Evidence Grade = C*). The tool is provided in Appendix A3 of the original guideline document.
- An algorithm developed to identify depression in adults in palliative care is the **Short Screen for Depression Symptoms** (see Appendix A4 of the original guideline document) (Robinson & Crawford, 2005. *Evidence Grade = C*) This algorithm is recommended because of the simplicity of administration and the intent of the assessment, which is to identify individuals in need of follow-up for depression.

Description of the Practice

Effective interventions for relieving spiritual distress in the terminally ill older adult focus on the core feelings of loneliness, social isolation, hopelessness, anxiety, and depression. While these interventions are not unique to this population, the evidence base reviewed for the interventions focused on the terminally ill older adult. These interventions, listed in the Spiritual Care Model and discussed below, may be considered broadly as psychosocial and physical connecting, and encouraging hope. Additional interventions for spiritual distress and promoting spiritual well being that may also be used with terminally ill individuals are described in an early evidence based guideline entitled *Promoting Spirituality in the Older Adult* (Gaskamp, Sutter, & Meraviglia, 2004) and in *Nursing Diagnoses, Outcomes, & Interventions: NANDA, NOC, and NIC Linkages* (Johnson, et al., 2001). Pain, anti-anxiety and antidepressant medications may be included in the medical plan of care for terminally ill older adults, so nurses would be administering medication and evaluating treatment responses, depending on the patient setting.

Connecting

Connectedness, feeling emotionally involved with others, is an innate human quality and powerful motivator for creating and maintaining relationships with other people. Without connectedness people may experience social isolation, deficits in belonging, and lack of meaning in life (Townsend & McWhirter, 2005. *Evidence Grade = D*). Feeling connected to other people provides people with protection from feelings of isolation and depression. A disruption in connectedness can cause psychological, social and physical disturbances (Lee, Draper, & Lee, 2001. *Evidence Grade = C*)

Easing Loneliness

- Little research has been conducted on the effectiveness of interventions for loneliness and social isolation. During terminal illnesses, older adults usually have diminished mobility and sensory limitations, which can compound their social isolation leading to loneliness (Pinquart & Sorensen, "Influence on loneliness," 2001. *Evidence Grade = A*). Needing assistance from others places extra strain on existing relationships and can impede their emotional needs being met.

Suggested interventions for those expressing loneliness are

- Including family members in activities and plans
- Learning new coping strategies, and
- Referral to mental health provider for individual psychotherapy (McInnis, 1999. *Evidence Grade = C*)

Although not specifically written to address the terminally ill older adult, Burkhardt and Nagia-Jacobson (2005. *Evidence Grade = D*) suggest the following strategies to promote connectedness:

- Encourage family and friends to visit the ill person
- Place photographs, pictures and mementos from loved ones within view of the ill person
- Talk about the special places, pets and things that are meaningful

- Bring pets to visit
- Encourage visits from people in community groups (faith community, social, business, school, interest groups, etc.)
- Connect with the environment by going outdoors, sitting near a window, having flowers or pictures of meaningful nature scenes in the room
- Connect with God through the practice of meaningful religious rituals

Referral to Mental Health Provider

In a meta-analysis of interventions for older adults with depression, Pinquart and Sorensen ("How effective", 2001. *Evidence Grade = A*) found cognitive-behavioral therapy and control-enhancing interventions were the most effective psychotherapy for improving sense of well-being. Individual interventions were also found to be much more effective than group interventions. Cognitive-behavioral therapy includes changing maladaptive beliefs to adaptive thinking and behaviors through challenging negative thoughts, developing problem solving abilities, and encouraging participation in enjoyable activities. Control-enhancing interventions focus on providing older adults control over their personal activities such as the structure of their day and completion of their activities of daily living. Long term interventions, over 10 sessions, were also found to be more effective than interventions that had a shorter duration. The studies included in the meta-analysis did not specifically address a terminally ill population, but older adults in general. Pinquart and Sorensen also concluded that therapists with gerontological or geriatric training were more effective than therapists without specialized training with the older population.

Palliative Care or Hospice Care

Palliative care or hospice care is a valuable community resource offering holistic and interdisciplinary care that is uniquely attuned to the needs of persons at the end of life. Persons receiving end of life care from hospice or palliative care providers report a reduction in anxiety, as well as better symptom management and better quality of life (Corner et al., 2003; Solà et al., 2004; Echteld et al., 2004; Jerant et al., 2004. *Evidence Grade = C*). Pastoral care is typically included in the interdisciplinary care team, so issues giving rise to spiritual distress are considered in the plan of care.

Physical Connectedness

Music, massage, and aromatherapy have been used in palliative care primarily as relaxation or stress reduction interventions that have short-term effects (Hemming & Maher, 2005. *Evidence Grade = D*).

- Physical touch provides a powerful sense of connection, yet may be as simple as handholding or an arm around the shoulders, and may be provided by family, friends, or caregivers (Burkhardt & Nagai-Jacobson, 2005. *Evidence Grade=D*).
- Touch and massage with or without aromatherapy have been used to ease anxiety in nursing home residents and persons with dementia, pain and anxiety (Fellowes, Barnes & Wilkinson, 2004; Robinson, Weitzel & Henderson, 2005. *Evidence Grade = D*). Massage may be provided by massage therapists, physical therapists, or nurses. In the study by Robinson and

associates, nursing assistants provided backrubs following the institution's backrub protocol. The backrub was the most requested aid for promoting sleep among patients on a hospital medical unit.

- Aromatherapy, with or without massage, has been used to achieve short term relief of anxiety in patients with cancer and in palliative care (Kuriyama et al., 2005; Kohara et al., 2004; Okamoto et al., 2005; Soden et al., 2004. *Evidence Grade = C*). However, the use of aromatic oils comes with caution because of the pharmacodynamic properties of oils and the potential interaction with other pharmacotherapeutics in use by the older adult. Scented oils also have the potential of skin irritation, and allergic reactions in persons who are sensitive to chemicals, thus training in the proper use of oils is essential (Dunning, 2005; Hemming & Maher, 2005; Lee, 2003; Maddocks-Jennings & Wilkinson, 2004; Perez, 2003; Thomas, 2002. *Evidence Grade = D*). Buckle (2005, *Evidence Grade = D*) describes a patented technique for gentle massage using light friction to apply essential oils. Information on training for this technique may be found at www.rjbuckle.com. Buckle also suggests scents of familiar fruits and flowers were beneficial for easing depression in ill elderly in residential settings.
- Music has long been associated with having calming effect (Salmon, 2001. *Evidence Grade = D*). Studies of the use of music therapy with hospice patients demonstrated positive effects on improving relaxation and ability to cope with anxiety, promote communication with family members, and a source of comfort, renewal, and release (Hilliard, 2001; Krout, 2001, 2003; Magill, 2001; Salmon, 2001. *Evidence Grade = D*). Music was effective whether provided live by a music therapist or by recording. A key to using music to enhance relaxation is to have the individual select music that is meaningful or important to him or her. If the older adult is unable to communicate music preference, a family member may be able to provide that information. Gerdner, (2001. *Evidence Grade C*) includes the following specific strategies for selecting music to be used in a therapeutic way:
    - Ascertain the importance of music for the individual prior to illness
    - Discuss specific music preferences, including song titles, performers, type (vocal or instrumental), type of instrumental (e.g. piano, organ, guitar, orchestral), genre
    - Use music from the individual's own music collection when feasible.

Encouraging Hope

Research has found that hope can be present even when a person is close to dying (Buckley & Herth, 2004. *Evidence Grade = C*). The dying person does not need to experience feelings of hopelessness and despair. Interventions for fostering hope for the terminally ill have been identified from research as assisting people to have affirming relationships, develop attainable goals, find meaning in their life, live in the present, use their inner resources, reflect on uplifting memories, and appreciate their personal value (Herth, 1990; Post-White et al. 1996. *Evidence Grade = C*).

Specific interventions, recommended in this guideline for redefining and encouraging hope in the terminally ill older adult, are based on current research (Cutcliffe & Herth, 2002; Davis, 2005; Buckley & Herth, 2004; Krisman-Scott & McCorkle, 2002; Morse & Doberneck, 1995; Parker-Oliver, 2002; Penrod & Morse, 1997. *Evidence Grade = C*).

- Develop caring and continuing interpersonal relationships with patients and their caregivers to facilitate a strong sense of belonging.
- Utilize inner spiritual resources to facilitate development of meanings and creation or implementation of important rituals and traditions.
- Address the fears of the dying person with specific activities and coping strategies as part of a care plan. Use reminiscence and life review therapies to identify past successful coping skills.
- Encourage patients to mend damaged relationships, say good-bye to others, give and receive forgiveness, and express their feelings openly.
- Work with dying patients to achieve their goals, asking them what they most want, and creatively working toward helping them get it.
- Utilize past experiences and systems of meaning to understand values and reinforce coping skills for the patient and family/caregivers.
- Identify significant losses that may be leading to feelings of hopelessness.
- Consider palliative/hospice care.
- Work with the physician to assure the dying patients that they do not need to die alone or be uncomfortable and that living will not be artificially prolonged.
- Create environments that ensure for adequate rest and relaxation of older adults.
- Assist dying patients and caregivers in finding ways to ensure that patients will be remembered.
- Encourage caregivers to find meaning in the dying process.

Appendix E in the original guideline document includes a compilation of Judeo-Christian scriptural references related to hope, comfort and joy that the older adult may find meaningful for easing spiritual distress.

Definitions:

Evidence Grading

The practice recommendations are assigned an evidence grade based upon the type and strength of evidence from research and other literature.

The grading schema used to make recommendations in this evidence-based practice guideline is:

A. Evidence from well-designed meta-analysis
B. Evidence from well-designed controlled trials, both randomized and nonrandomized, with results that consistently support a specific action (e.g., assessment, intervention, or treatment)
C. Evidence from observational studies (e.g., correlational descriptive studies) or controlled trials with inconsistent results
D. Evidence from expert opinion or multiple case reports

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

REFERENCES SUPPORTING THE RECOMMENDATIONS

References open in a new window

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is identified and graded for each recommendation (see "Major Recommendations").

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Appropriate provision of spiritual care to terminally ill older adults to provide:

- Spiritual well-being (absence of feelings related to spiritual distress)
- Connectedness (decreased sense of loneliness and social isolation)
- Hopefulness (improved sense of hope)
- Decreased depression

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

For the purposes of this guideline, it is assumed that supportive nursing care and symptom management for conditions related to the terminal illness, such as pain or respiratory distress, is provided.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Process Indicators

Process Indicators are those interpersonal and environmental factors that can facilitate the use of a guideline. One process factor that can be assessed with a sample of nurses/& physicians is knowledge about providing spiritual care to the terminally ill older adult. The **Providing Spiritual Care Knowledge Assessment Test** (See Appendix B in the original guideline document) should be completed before and following the education of staff regarding use of this guideline.

The same sample of nurses, physicians or other care givers for whom the Knowledge Assessment Test was given should also be given the **Process Evaluation Monitor** (See Appendix C in the original guideline document) approximately one month following his/her use of the guideline. The purpose of this monitor is to determine his/her understanding of the guideline and to assess the support for carrying out the guideline.

Outcome Indicators

Outcome indicators are those expected to change or improve from consistent use of the guideline. The major outcome indicators that should be monitored over time are:

- Spiritual well-being (absence of feelings related to spiritual distress)
- Connectedness (decreased sense of loneliness and social isolation)
- Hopefulness (improved sense of hope)
- Decreased depression

The *Providing Spiritual Care to the Terminally Ill Guideline Monitor* described in Appendix D in the original guideline document is to be used for monitoring and evaluating the usefulness of the guideline in improving the quality of life of the terminally ill older adult. Please adapt this outcome monitor to your organization or unit and add outcomes you believe are important.

IMPLEMENTATION TOOLS

Audit Criteria/Indicators
Chart Documentation/Checklists/Forms
Resources
Staff Training/Competency Material

For information about availability, see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Meraviglia M, Sutter R, Gaskamp CD. Providing spiritual care to the terminally ill older adult. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core; 2006 Dec. 45 p. [106 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2006 Dec

GUIDELINE DEVELOPER(S)

University of Iowa Gerontological Nursing Interventions Research Center, Research Translation and Dissemination Core - Academic Institution

SOURCE(S) OF FUNDING

Not stated

GUIDELINE COMMITTEE

University of Iowa Gerontological Nursing Interventions Research Center Research Development and Dissemination Core

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Not available at this time.

Print copies: Available from the University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core, 4118 Westlawn, Iowa City, IA 52242. For more information, please see the University of Iowa Gerontological Nursing Interventions Research Center Web site.

AVAILABILITY OF COMPANION DOCUMENTS

The original guideline document and its appendices include a number of implementation tools, including screening tools, outcome and process indicators, staff competency material, and other forms.

PATIENT RESOURCES

None available

NGC STATUS

This NGC summary was completed by ECRI Institute on May 4, 2007. The information was verified by the guideline developer on May 15, 2007. This summary was updated by ECRI Institute on November 9, 2007, following the U.S. Food and Drug Administration advisory on Antidepressant drugs.

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Date Modified: 10/20/2008